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Reframing healthcare transition: Systems, relationships, and independence in adolescent-to-adult care

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ABSTRACT

This article summarizes the findings from a roundtable convening led by the organization Generation Patient between patients, healthcare providers, and researchers on the transition from pediatric to adult care, identifying barriers at both within the clinic and broader system levels, including the need for improved self advocacy skills, tailored care approaches for patients with complex care needs, and systemic supports such as transition navigators and social workers. Recommendations include enhancing patient independence during pediatric care, adopting a multidisciplinary team approach, and implementing long-term system reforms such as improved adult provider training and Medicaid policy changes. These insights present a call to action for healthcare stakeholders to share responsibility and take a more active role to ensure patients with chronic conditions receive the appropriate care after they transition from pediatrics.

Introduction: Transition from pediatric to adult care remains a significant challenge for adolescents and young adults (AYAs) with chronic conditions. Insufficient preparation and support during this period can lead to increased morbidity and gaps in care. Existing systems often place the burden of transition on patients and families, resulting in unmet needs for self-advocacy skill development, tailored care approaches for diverse populations, and system-level supports.

Methods: A roundtable was convened by the young-adult-led advocacy organization Generation Patient, involving 9 healthcare professionals (physicians, nurses, social workers, researchers, transition specialists) and 11 young adult patients from across the United States. Discussions were structured to elicit experiences and recommendations regarding barriers and solutions for healthcare transition. Qualitative analysis of the proceedings identified key themes and consensus recommendations.

Results: Participants highlighted that current transition processes are abrupt and emotionally taxing for AYAs, especially those with complex or rare conditions and neurodevelopmental differences. Barriers included limited preparation for patient independence, lack of individualized care models, insufficient system supports, and challenges with insurance and provider handoffs. Recommendations focused on early promotion of independence within pediatric care, personalized approaches for patients with varied needs, integration of transition navigators and case managers, and upstream reforms such as Medicaid policy changes and enhanced adult provider training.

Conclusion: A successful transition from pediatric to adult care requires moving beyond solely individual patient solutions toward system-wide, collaborative responsibility. Engaging multidisciplinary teams, supporting patient autonomy, and implementing policy reforms are essential steps to ensure continuity and quality of care for AYAs with chronic conditions.

1. Introduction

Healthcare transition is a growing field centered on supporting the transfer of adolescents and young adults (AYAs) with long-term conditions from pediatric to adult care services [1]. A successful transition process not only prepares AYAs to independently manage their

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healthcare needs but also equips them to navigate the complexities of adult-oriented healthcare systems.[1] Despite its importance, most AYAs do not receive adequate transition planning or support; recent national data indicate that fewer than 20 % of youth receive recommended healthcare transition services.[2] Inadequate preparation for this transition can lead to serious negative outcomes, including increased morbidity and mortality.[3]

While the field of healthcare transition has historically categorized adolescents and young adults (AYAs) as a single subgroup, we contend that these two groups face distinct and unique challenges that warrant separate consideration. For example, adolescents are undergoing rapid physiological development, including puberty-related hormonal changes and ongoing brain maturation. Socially, developing adolescents are navigating significant social transitions such as increased autonomy from parents and the complexities of peer relationships. Young adults face a different set of challenges, including the assumption of independent healthcare decision-making, employment or higher education transitions, and the establishment of long-term personal and professional identities. Young adults are often at a different physiological development phase and while physiological changes are anticipated, psychosocial development may continue to lag behind for some young adults with various cognitive impairments. Recognizing these differences is vital for determining effective support and interventions within the healthcare transition process.

Generation Patient is a nonprofit organization created by and for young adults living with chronic conditions such as lupus, inflammatory bowel disease, Lyme disease, rheumatoid arthritis, and others. To address the persistent challenges of healthcare transition across disease groups, Generation Patient convened a roundtable discussion between patients, healthcare professionals, and researchers. This roundtable was composed of 9 healthcare professionals and 11 young adult patients. Healthcare professionals included physicians, nurses, social workers, researchers, and transition specialists from institutions across the U.S., including Boston Children's Hospital, Children's Hospital Los Angeles, the National Alliance to Advance Adolescent Health, Baylor College of Medicine, and the University of Southern California Keck School of Medicine.

Patient participants described the transition as "violent," highlighting the emotional and practical difficulties AYAs face when shifting from a child to an adult healthcare system where they often experience a sudden change in how they are treated. Healthcare providers also reported challenges with caring for AYAs during the transition period, citing both clinic-level and systemic barriers to effectively supporting this patient population. Both healthcare providers and patient roundtable participants identified suggestions for addressing barriers to a successful transition at a systemic level, shifting the narrative away from transition success primarily being the patient's responsibility. A key takeaway from the discussion was the need for healthcare providers to take a more active role in guiding patients through this process, rather than leaving families to navigate it alone.

Empowering healthcare providers to support independence while ensuring patients receive tailored care is essential for a successful transition. Our roundtable participants also identified the importance of providing support for AYAs in navigating the healthcare system, highlighting the importance of integrating case managers and navigators into the transition process for AYA patients. This proceedings document summarizes the roundtable discussion and provides a call to action for clinicians, healthcare systems, and community members.

2. Inside the clinic: transition challenges and opportunities

Suggestions for improving the transition process at the level of the patient-provider relationship in pediatric care were identified by roundtable participants, with patient participants emphasizing the need to develop self-advocacy skills early on. Young adult patients articulated their needs directly, stating, "Give us the skills and knowledge we need to manage our healthcare independently. Build a relationship with us. Talk to me, not my parents." This sentiment exemplifies a fundamental desire for autonomy and respect that is at the core of successful transitions. Physicians acknowledged their role in creating space for independence, with one provider noting, "If somebody doesn't start coming in entirely on their own until they're 20, and are bringing their parents with them when they're 18 and 19, it actually doesn't cause a lot of trouble compared to many of the other things that happen when transitioning to adult care, but without having time alone with the doctor at 18 and 19 years old I don't think preparation occurs." This observation showcases how incremental steps toward independence, such as solo provider conversations, serve as building blocks in the development of healthcare self-efficacy, potentially mitigating many of the challenges inherent in the transition process.

Another challenge identified by both patients and healthcare professionals was the need for personalized and responsive care approaches, particularly for neurodivergent and other underserved populations. One physician emphasized the difficulty in managing patients with neurodevelopmental disabilities within the Massachusetts healthcare system, pointing out that many of these patients are unable to advocate for themselves or navigate the complexities of medical care, such as medication management, appointment scheduling, or insurance issues. This challenge requires a tailored clinical approach that recognizes the cognitive and sensory abilities of each patient. As one provider explained, "You approach your patient depending on what their cognitive abilities are," emphasizing the importance of individualized care models. Regardless of ability, every patient should have the opportunity to learn self-advocacy skills, guided by supportive healthcare professionals.

Participants also expressed concerns about the limitations of "one-size-fits-all" models for those with rare diseases. One patient recounted their frustration when a rheumatologist, uncertain about how to proceed, admitted, "I actually don't know what to do with you." This exemplifies the critical need for specialized support, such as complex care nurses who can coordinate across multiple specialties and ensure that patients with rare diseases receive the comprehensive, cohesive care they require. Responsive care also requires cultural awareness. For example, one participant shared, "My parents are both immigrants, so I've seen the aspect of my mom being a little bit more apprehensive with approaches to care."

The experiences shared by roundtable participants indicate a need for a cultural shift toward pediatric care models that promote patient independence, while recognizing that robust systemic support structures are essential to facilitate successful healthcare transitions for all patients. Engaging all members of the healthcare team, especially registered nurses (RNs), can also help support successful healthcare transition for young adult patients. The relationship-based model of care that is central to nursing practice can be leveraged to support patients as they navigate increasing independence with their medical care. Furthermore, calls for systemic changes, like implementing medical wait time limits or streamlining the process for prescription refills and insurance inquiries, were voiced as necessary steps to alleviate the added stress these patients face during their transition into adult healthcare.

3. Outside the clinic: systems-level barriers and solutions

Throughout the discussion, it became clear that the transition from pediatric to adult healthcare requires a system that prioritizes multidisciplinary collaboration and adopts a biopsychosocial-oriented framework of care to "broaden our understanding of strategies that would be needed to affect some of the cultural changes." This collaboration may involve primary care physicians, specialty providers, social workers, case managers, educational and vocational counselors, psychologists, and mental health care providers.

Both healthcare providers and patients emphasized that navigating the healthcare system independently is one of the most significant challenges for young adult patients. Participants identified several specific system-level barriers, including understanding complex health insurance coverage, refilling specialty medications, and managing multiple appointments with subspecialists. This sentiment was echoed by a patient participant who identified insurance navigation as a critical obstacle: "That is the number one thing for me was managing and finding health insurance. Transition to adult care was not even an option for me because I didn't have insurance to begin with." Even highly educated patients described significant challenges. As one noted, "Every time that I am on multiple phone calls with the copay support program for the biologic that I take, I think, wow, this is really hard for me–and I have an advanced degree in health services research, and I'm struggling here."

Participants further acknowledged a "lack of support for the non-medical aspects in the transition process," explaining that clinicians "tend to focus on the disease management side… and there's really so, so much more beyond that." This demonstrates the importance of addressing what one pediatric advanced practice nurse termed "adulting" skills alongside medical management. It was suggested that dedicated transition navigators could significantly improve outcomes for patients during this vulnerable period, when young adults are often navigating multiple life transitions outside the medical system as well, such as living independently for the first time or starting college or a new job.

Roundtable participants emphasized the integration of social workers, case managers, or transition navigators into care teams as a solution to ensure non-medical challenges are appropriately addressed. Previous research supports the importance of these roles in facilitating successful transitions for young adult patients, particularly those who are socioeconomically vulnerable.[4–6]

The roundtable discussion identified significant systemic barriers requiring fundamental reform in both pediatric and adult healthcare domains. Participants stressed the need for upstream training modifications, particularly in residency education and promoting earlier patient independence. As one healthcare provider noted, participants stressed the importance of introducing upstream changes, particularly in residency education, to foster earlier patient independence and better prepare clinicians for transition care. As one provider observed, "We place a lot of onus on the patient, and as a medical system, we have to take on more of the responsibility. Patients cannot be expected to manage things like insurance when they're sick and not well to begin with."

Healthcare providers at our roundtable cited the importance of changing how healthcare providers approach transition, starting early in their training. They specified that these changes needed to begin at the healthcare system level by changing how the care of transition-age patients is approached in medical training: "Somehow we have to bake that into training, so medical students, residents, fellows need to have that skill set." Additionally, we recommend systemic changes to make the field of medicine more accessible, thereby increasing the number of clinicians with disabilities who can provide concordant care to this population. While the majority of the discussion focused on changes that could be made in pediatric care, it is also important to consider how healthcare systems can support the adult healthcare provider workforce to ensure that there are sufficient adult healthcare providers who are trained and willing to accept AYA patients with complex medical needs.

4. Recommendations and call to action

We recommend the following short-, medium-, and long-term goals to improve healthcare transitions for AYA patients, both at the individual clinic or encounter level and on a larger systems level. Short-term goals can be addressed at the individual clinic or encounter level. We recommend increasing independence for adolescent patients while they are still in pediatric care. This can include time alone with their healthcare provider and a gradual shift towards increased self-management responsibility during the visit and at home. This aligns with the American Academy of Pediatrics guidelines, which call for "emphasis on self-determination, self-management, and family and/or caregiver engagement"[7] in healthcare transition preparation. With this in mind, we also want to acknowledge the diversity of patients that exists and reiterate that effectively supporting the independence and autonomy of young patients requires a tailored clinical approach that accounts for the individual's cognitive and sensory abilities.

As a medium-term goal, we recommend a shift to a multidisciplinary approach to healthcare transition at the healthcare system level, especially in adult care where fewer such teams exist. Specifically, we recommend integrating dedicated transition navigators or case managers into the care team to provide comprehensive support to AYAs as they learn to navigate the healthcare system independently. Finally, as long-term goals, we recommend addressing system-level barriers, including training more adult providers in the care of young adult patients and increasing access to health insurance coverage for AYAs. Reforming the Medicaid recertification process, which in many states occurs at age 19, is essential to ensuring that vulnerable AYAs maintain critical access to health insurance coverage during the transition period. Furthermore, we believe it is essential to acknowledge that changes within the executive branch and the accompanying policy shifts can significantly impact the transition of care for young adults with chronic conditions. With each new administration, it remains vital for healthcare professionals and patient communities to elevate the voices of young adult patients and ensure that systemic decisions are informed by the lived experiences of those most affected.

5. Conclusion

As evidenced by our roundtable discussion, improving healthcare transitions requires a multi-layered approach addressing both clinic-level practices and broader systemic barriers. Ensuring successful transitions means equipping young patients with the knowledge and skills they need early and incorporating dedicated support roles like transition navigators and social workers within care teams, as well as reforming healthcare systems to better train adult providers and secure continuous insurance coverage.

In addition to recommending improvements in healthcare transition through clinic and systems-level changes, we also recognize the importance of focusing research efforts on measuring the biomedical, behavioral, and emotional outcomes of healthcare transition.[8] Rigorous outcomes measurement is historically lacking in healthcare transition research, yet it is key to identifying the impact of interventions aimed to support successful transitions. Ultimately, shifting the burden of transition away from patients and toward a collaborative, well-supported framework will not only improve health outcomes but also promote autonomy, resilience, and long-term well-being for AYA patients navigating complex healthcare landscapes.

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Katherine Melton: Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis. **Susan Shanske:** Writing – review & editing, Writing – original draft, Conceptualization. **Sneha Dave:** Writing – review & editing, Conceptualization. **Sydney**

Reed: Writing – review & editing, Writing – original draft, Project administration, Conceptualization. **Caroline Walsh:** Writing – review & editing, Writing – original draft, Formal analysis, Conceptualization.

Declaration of Competing Interest

The authors have no conflicts of interest to disclose.

Data availability

No data was used for the research described in the article.

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